

TO:
Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services
Senator Martin Nesbitt, Co-Chair
Representative Verla Insko, Co-Chair
February 14, 2006

Senator Nesbitt, Representative Insko, and Members of the Committee:

Thank you for the opportunity to offer comments to the Legislative Oversight Committee on barriers to consumer involvement in Consumer and Family Advisory Committees (CFAC) and challenges faced by members of the committees. In preparing these comments, I drew on my own experience and that of CFAC members around the state who were willing to give their input. All are not represented. The barriers and challenges are not found in all committees. Likewise, some CFAC's are already doing the things that the recommendations lay out. I hope, however, that these comments will assist you in your discussions about the management capacity needed to support successful Consumer and Family Advisory Committees.

Successes described by CFAC members:

1. Involvement in grant writing to support program initiatives not funded by the Division or Medicaid
2. Input into the review process for RFP's submitted by providers
3. Creation of a consumer ID card program, making identification cards available free to any consumer in the LME catchment area; cards include information about illness, medications, emergency contacts, etc.; beneficial for emergency situations where documentation is needed or when a person can't communicate due to illness or injury
4. Planning for new programs – example given - Peer Support initiatives
5. Planning for new programs – example given - Jail Diversion; CFAC participation in interviews with the judges and attorneys who would have a crucial role in the program's success
6. CFAC subcommittees created to address a specific issue, for example, one community's concern about a shortage of qualified home assistants and out-of-home activities for families with developmentally disabled members
7. Ongoing process of fine-tuning the ByLaws and Subcommittee structure to provide direction and focus to the members.
8. Issue-based subcommittees that combine their efforts with other community agencies/committees to increase efficiency, eliminate duplication, and promote understanding in the community.
9. Development of a Mystery Shopper program to assist in LME monitoring of providers.
10. Holding public forums and town hall meetings during Mental Health Month (May) and Mental Illness Awareness Week (October)

Comments on barriers to involvement and challenges faced by the CFAC:

1. **FIRST, A GENERAL STATEMENT:** The premise and formation of Consumer and Family Advisory Committees in response to Mental Health Reform Legislation in North Carolina is to be commended. It is an unprecedented step toward valuing the role of consumers and families in treatment, recovery, and rehabilitation. The idea is still relatively new and requires a shift in mindset that will not happen overnight. We have a big ship to turn around with resources that seem to become more scarce every day. That said, the creation of the CFAC, a formalized local and state committee which is representative of disabilities, age, race, and geographic locations,

has set the stage for a formalized voice in directing services in North Carolina. The challenges are many and the road so far has been bumpy and uneven. What seems like a simple and obvious idea is not so simple to implement. We are, however, learning from the early mistakes and misdirections and I am confident that meaningful consumer and family involvement will eventually become the norm.

2. The LME needs a better outline of roles and functions, as well as clearer guidance in how to support the CFAC and allow the valuable input that these consumer and family representatives bring to the table. Whatever guidelines were written when this process started, refinement and update is needed. The Advocacy and Customer Service section did not even exist when many CFAC's were forming. With little initial guidance, and faced with the task of writing a local business plan, which the CFAC was supposed to help write, and then read, study, and evaluate, each LME created a CFAC that was likely a reflection of its current management style. It is time to revisit the structure and role of these committees.
3. Consumers have been accustomed to seeing others advocating for them, when what they really need is support to be encouraged to come forward and use their own voices to shape policy.
4. There is the perception that the CFAC is not given the power and respect it deserves at either the LME or the Division level.
5. Some Area Programs did not want the CFAC in the first place. Some Area Directors felt that there were already enough boards, advisory groups, and committees for sufficient input.
6. An LME with a proactive, progressive management style increases the likelihood that the CFAC will be recognized as a credible voice and will be successful in its work. Not every Area Program/LME is viewed as being progressive.
7. Getting consumer representation from the substance abuse area and from the child mental health/substance abuse area is very challenging due to the nature of these disabilities on top of the all the other responsibilities that parents face.
8. In parts of the state where the LME covers large geographical areas, transportation and excessive miles to travel to meetings inhibits the success of, as well as the representation on, the CFAC.
9. Some committees are too LME driven and do not take on challenges as a group. They are led by the LME and learn from them, rather than the other way around. They do little advising.
10. Consumers do not know about the CFAC. The message is not getting out in a meaningful way to the people who need to know that this opportunity exists.
11. There has been resistance to requests for reimbursement for gas or other expenses, with statements that the Division was not providing funds to support the CFAC and there weren't funds in the local budget for this expenditure.
12. Stigma is a barrier to membership recruitment; as one person put it, "When you are on the CFAC, you're out of the closet."
13. In order for the CFAC to adequately represent the general population we must be known and be accessible at the local level. We have discussed this often and no one really has any reasonable means as to how to resolve this. We need help in becoming less verbal and more action-oriented. In other words we are all talk and no action. We, too, need recommendations.
14. Meeting schedules are always a challenge.
15. Members are often people who are doing other things related to mh/dd/sa issues, so you get people who are already busy.
16. A CFAC is a group of ordinary citizens, many of whom come without extensive knowledge about how the entire system works. Members may have a good understanding of one disability area but know absolutely nothing about another.
17. The CFAC process has the expectation of executive-level functioning from a group of citizen-advisors who may have the passion but not the management skills.
18. The lingo and acronyms found in documents are a constant challenge.
19. People don't understand the finances – where the money comes from and how it is used.
20. Members often don't understand the degree to which politics can drive decisions.

Recommendations for a more effective CFAC:

1. Require (in the words of a member who sent comments to be included in this document) that the CFAC have a more meaningful role in the LME. It seems the LME must be convinced of the validity and importance of the CFAC. People are still asking “When are you going to start listening to us?”
2. Develop a better outline for the LME of roles and functions, as well as clearer guidance in how to support the CFAC.
3. Assess the number of LME citizen committees, boards, task forces, etc., whether state mandated or locally created. Review their mission and purpose. Is there duplication? Is the need still current? Can any be disbanded? Members of other committees may fit the criteria for the CFAC or one of its subcommittees. Every committee requires staff time, which eventually becomes the justification for opposing the formation of a new committee.
4. Staff the CFAC with a competent, professional, dedicated LME liason who believes in the committee’s value. This person must communicate energy, enthusiasm, appreciation for the committee members’ involvement, and a can-do attitude. The staff to the committee plays a significant role in driving the administrative tasks. CFAC members are ordinary citizens who have the passion but not necessarily the executive skills.
5. Inform the communities served by the LME about the CFAC. One-time notices, one-time public meetings, and one-time distribution of brochures are not enough. The process is a continuous one that requires a marketing plan. Whose responsibility is it?
6. Monitor potential conflicts of interest when recruiting for the committee. Language about who must be on the committee might also need to specify who should not be on the committee.
7. Make the original CFAC documents about the structure, purpose, and organization of the committee drive the agenda. Revisit the Bylaws regularly. The authority given to the CFAC through legislation must be explained and discussed frequently. It must be woven into the work of the committee so that members understand that their opinions matter.
8. Make CFAC information available, and current, on the county and/or LME website. It must be easy to find. It can serve as an advertisement for the committee and offer news about the committee’s work. If the CFAC has a newsletter, post it online. The Area Programs/LME’s have not fully institutionalized the Internet as a tool, yet it has become the first place that millions of our citizens, especially if they are under 35, go first. The Internet also helps make an organization more transparent, which some view as a good thing and others do not.
9. Give CFAC members training in navigating the Division website and other state or non-profit websites that have educational value. Provide computers with Internet connections at the meetings. Members may not know what is on the Division website, what the documents mean, or the connection between that information and the committee’s work.
10. Examine the process by which a CFAC does its work. A CFAC may give advice, then tasks are delegated to staff. The CFAC may do the work along with the staff. Or the CFAC may take on a project and do all the work. Feeling ownership of a project is important to consumer involvement, whether it comes from working in the planning process or from direct involvement in implementation. Additionally, community stakeholders need to see consumer involvement in a program to fully recognize its importance.
11. Create CFAC subcommittees that are issue-related. Give the chair the flexibility to add non-CFAC members as a resource or collaborate with other community groups on the issue. Subcommittees can be standing or time-limited.
12. Provide and encourage networking opportunities for CFAC members. The CFAC regional meetings have been valuable and worthwhile. Find additional ways for members to see how the CFAC operates in other areas, including attending CFAC meetings to get a first-hand look at committee dynamics and meeting styles.
13. Create business cards for CFAC members to use as a networking and marketing tool, in addition to CFAC brochures. Train committee members to find opportunities engage in conversations about the CFAC and pass along the brochure and contact information.

14. Educate local government staff and elected officials about the CFAC. In areas where mental health services have operated in a somewhat isolated fashion relative to other areas of local government, it is important for those people to see us in a more normalized way.
15. Recognize volunteers (and the number of volunteer hours) for their contributions.
16. Anticipate that the current CFAC model may need revision as the state moves toward fewer and larger LME's.

Respectfully submitted,
Carol Matthieu, Vice Chair
Rockingham County Consumer and Family Advisory Committee